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Sharing a secret: Disclosure practices among adolescents and young adults with chronic illness

Kaitlin Venema[1] · **Bridgid Mariko Conn**[2] · **Diane Tanaka**[2] · **Karl Silge**[3] · **Ellen Iverson**[2]

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Abstract

Objective: Peer support is an essential component of adolescence and is instrumental in reducing feelings of isolation and loneliness. Yet, many youth and young adults experiencing a chronic medical condition conceal or minimize aspects of their conditions due to feared rejection. Disclosure practices in adolescents with chronic illnesses are not well-studied with little known about the nature of information disclosed. This study sought to better understand the relationship between the depth of information disclosed to friends and health-related quality of life, response to stress, and coping strategies. **Methods**: The sample consisted of 140 patients between the ages of 15–21 years who were recruited from seven sub-specialty medical clinics. Quantitative data was collected from a baseline survey examining disclosure, coping, and health-related quality of life. **Results**: Three groups were created and compared based on participant responses to the types of information being disclosed to friends: No Disclosure, Facts, and Concerns/Emotions. Participants who disclosed the psychological impact and concerns related to their condition tended to be female and had a significantly higher number of friends to whom they disclosed. This group of participants also tended to endorse higher levels of illness-related stress and was engaging in more positive coping strategies than those who chose not to disclose information or only shared objective information about their conditions. **Conclusion**: Understanding of the nuances of the depth and decision-making of disclosure is necessary for providers to be able to support youth with chronic illness as they navigate their social environment and relationships.

Keywords Chronic illness · Adolescents and young adults · Disclosure · Quality of life · Coping · Stress

Introduction

Background

A sense of belonging is a key component of healthy adolescence and peer support is critical to the mental and physical health of a young person. For adolescents living with a chronic medical condition, peer support can be instrumental to reducing adolescents' feelings of isolation and loneliness and improving treatment management (La Greca et al., 1995, 2002) Yet, adolescents living with chronic medical conditions often feel the need to conceal aspects of their illness from peers due to feared stigma and rejection (Kaushansky et al., 2017; Quinn & Chaudoir, 2009), despite the fact that disclosure of illness-related information and/or diagnosis has been identified as a "central" experience of living with chronic illness (Woodgate et al., 2020). This population is faced with a dilemma, weighing the risk of stigmatization if their condition is revealed with risks to physical and mental well-being should the condition remain concealed (Vickers, 1997). The limited literature examining disclosure among adolescents with chronic illness suggest that the decision to disclose is purposeful and most are likely to consider several factors that inform their decision to share with others (Woodgate et al., 2020). The increased anxiety and stress

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✉ Ellen Iverson
ellieiverson2@gmail.com

[1] Division of Adolescent and Young Adult Medicine, Children's Hospital Los Angeles, 4650 Sunset Blvd., Mailstop #2, Los Angeles, CA, USA

[2] Department of Pediatrics, Keck School of Medicine, Division of Adolescent and Young Adult Medicine, University of Southern California, Children's Hospital Los Angeles, Los Angeles, CA, USA

[3] Department of Preventive Medicine, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA

of this decision-making process adds additional burden of elevated distress, depression, anxiety, guilt, and social isolation not uncommon among youth living with chronic illness (Benson et al., 2015; Donoghue, 2012).

While the prevalence of chronic illnesses among adolescents grows, disclosure practices, coping strategies, and quality of life in this population remains understudied (Andes et al., 2020; Perrin et al., 2007). Youth living with chronic illness face challenges and stressors managing their condition while simultaneously navigating adolescent developmental milestones. Limitations in engaging in age-appropriate activities, reliance on long-term treatments, necessary medication adherence, and acute medical events, such as hospitalization, differentiate this population from same-aged peers and can impact quality of life. Pediatric populations with chronic illnesses have been found to have impaired physical well-being and peer/social support compared to healthy peers (Silva et al., 2019).

There is growing interest in the coping strategies adolescents and young adults (AYA) employ in response to the stress of living with a chronic illness. How various coping strategies affect health outcomes of adolescents with medical complexity has been studied across several chronic conditions. Among adolescents with diabetes, behavioral and mental disengagement, planning, and instrumental support have been associated with poorer quality of life and health outcomes. Social support and cognitive restructuring have been associated with positive well-being (Edgar & Skinner, 2003; Graue et al., 2004; Jaser & White, 2011). In studies of multiple conditions, more passive or disengaged coping strategies (i.e., avoidance, denial, wishful thinking) were found to lead to poorer adjustment, though evidence of associations between active coping and positive health-related adjustment is less consistent (Compas et al., 2012). Identifying patterns of coping within the context of varying disclosure practices may help clarify the role of social support in managing illness-related stress.

The fear of stigma can create a barrier to accessing peer support shown to increase optimism and lessen a sense of isolation in adolescents with chronic illnesses (Nabors et al., 2015). Consistent with Goffman's stigma theory, adolescents may prefer to conceal their conditions to "fit in" and avoid being treated differently or experiencing rejection and discrimination (Goffman, 1963). It is not uncommon for a young person who discloses to peers to minimize the gravity of the condition to project a "sense of normality" (Monaghan & Gabe, 2015). Concealing a chronic condition may add to psychological stress or feelings of guilt about withholding information from those they care about (Derlega, 1993). If disclosure reduces concerns about anticipated stigma, it may help to improve overall well-being, particularly when disclosure encourages others to be open about their own identities, further fostering connections to others (Chaudoir & Fisher, 2010).

Few studies have explored decision-making and patterns of disclosure as adolescents enter adulthood through a developmental lens (Kaushansky et al., 2017; Woodgate et al., 2020). Disclosure during this developmental period can be complicated by heightened fear of rejection as adolescents strive to socially conform and explore their social identities. Most research examining disclosure of a medical condition among adolescents have focused on specific conditions, such as epilepsy, HIV/AIDS, and cystic fibrosis (Barker et al., 2012; Benson et al., 2015; Di Risio et al., 2011). For instance, Barker and colleagues' study of disclosure among adolescents with cystic fibrosis found that they tended to inform most friends of their diagnosis in their social networks and consequently received treatment-related and relational support (e.g., encouragement, sense of belonging) (Barker et al., 2012). A qualitative study by Kaushansky and colleagues examining AYA with a variety of visible and "invisible" chronic health conditions found that many expressed fear that disclosure would lead others to misunderstand their condition or feel pity despite evidence that few participants reported experiencing rejection, pity, or isolation resulting from disclosure (Kaushansky et al., 2017).

Studies examining commonalities of AYA disclosure-related decision-making and practices across conditions remain limited. Specifically, little is known about what information is being disclosed and the impact of disclosure practices on psychological health. This study seeks to understand the relationship between disclosing illness-relevant information, mental health symptoms, and health-related quality of life in AYA with diverse chronic illnesses. We examine the association between coping strategies and response to stress and disclosure practices. It is hypothesized that participants with greater illness-related psychological distress will be more likely to disclose personal information related to their illness, such as emotional and psychological concerns, to friends in an effort to increase social support to manage their health-related worries. Deepening our understanding of disclosure practices and health-related quality of life in this formative developmental period can provide insight regarding ways to strengthen support for young people navigating the challenging social dynamics of adolescence and young adulthood while coping with the stresses of living with chronic illness.

Methods

Study design

This study was conducted at the Division of Adolescent and Young Adult Medicine (DAYAM) at Children's Hospital Los Angeles (CHLA), the largest pediatric tertiary care institution in the Western US providing "safety net" pediatric care to the diverse communities of Los Angeles and surrounding counties. The DAYAM at CHLA partnered with seven sub-specialty clinics to establish the MyVOICE Adolescent Transition Clinic, a program that addresses the unique needs of adolescents with chronic medical conditions as they prepare to transition to adult systems of healthcare. Participants for the study were recruited from the MyVOICE clinic following approval from the Institutional Review Board. Participants completed a baseline survey designed to evaluate the impact of exposure to the transition program on successful linkage to adult care, health status and utilization, and psychosocial health. The baseline survey assessed health status, adherence to treatment, knowledge of their condition and psychological and social factors (e.g., response to stress, coping, relationship with parents, quality of life, and disclosure of illness to others). A priori power analyses were conducted to inform decisions about the size of the sample to be recruited for the overall study.

Table 1 Demographic characteristics for study sample. (N = 140)

Age	Range = 15–21 years	Mean = 18.5 (SD = 1.4)
		No. (%)
Race/Ethnicity	Latinx/Hispanic	114 (81.4%)
	Asian	9 (6.4%)
	Black/African American	8 (5.7%)
	White/Caucasian	4 (2.9%)
	Pacific Islander	3 (2.1%)
Gender Identity	Female	96 (68.6%)
	Male	44 (31.4%)
Sexual Orientation	Heterosexual/straight	122 (86.5%)
	Gay or lesbian	2 (1.4%)
	Bisexual	7 (5.0%)
	Fluid/Questioning/Other	3 (2.1%)
Childhood Household Income (perceived)	Low-income/poverty	71 (50.5%)
	Middle-Income	43 (30.5%)
	Upper-middle income/wealthy	8 (5.7%)
Income Source (participant)	Family	89 (63.6%)
	Work	26 (18.4%)
	Disability	14 (9.9%)
	Public Assistance	4 (2.9%)
	Other (none/combination)	2 (1.4%)
	Friend	1 (0.7%)
Relationship Status	Single	93 (66%)
	In a relationship/married	44 (31.4%)
Education Level	In high school	31 (22.1%)
	Completed high school	55 (39.3%)
	Completed some college	29 (20.7%)

Data for the baseline survey were collected between 2014 and 2017. New or recently enrolled patients who participated in the MyVOICE clinic were invited to participate in a study of transition to adult systems of care. Once consented, participants completed the survey using the study computer in a private room which took 45 min to an hour to complete. If the participant was unable to complete the survey during their visit, the study team scheduled a phone interview with the participant using document-sharing software allowing the participant to self-administer the survey online with the interviewer available to answer questions and troubleshoot. Participants were reimbursed for their time completing the survey.

Participants

Inclusion criteria for the MyVOICE program and study eligibility were: (1) cognitively capable (determined by study staff), (2) English or Spanish speaking, (3) transitional aged youth between 15 and 21 years of age, and (4) referred to the MyVOICE program by one of seven subspecialties with which the program partnered (see below). A sample of 140 AYA enrolled in the MyVOICE program aged 15–21 years old (mean = 18.5 years; *SD* = 1.4 years) were recruited into the study. Study demographics appear in Table 1. Participants were primarily Latinx/Hispanic (81.4%), over two-thirds (68.6%) of the sample identified as female, and 92% of the sample were Medicaid eligible. Participants were referred from the following subspecialties (diagnoses): Rheumatology (e.g., juvenile idiopathic arthritic, systemic lupus erythematosus, scleroderma) (45%), Nephrology (e.g., chronic kidney disease, kidney transplant) (23%), Cardiology (e.g., congenital heart disease, cardiomyopathy, pulmonary hypertension, heart transplant) (11%), Pulmonology (cystic fibrosis) (7%), Gastroenterology (e.g., Inflammatory Bowel Disease, liver transplant) (9%), Bone Marrow Transplant (e.g., leukemia) (2%), Hematology (e.g., sickle cell disease, thalassemia) (2%), and Other (1%).

Measures

Disclosure

At the time of this study, there were no developmentally appropriate measures of disclosure validated with AYA with chronic illness that addressed the breadth and depth of illness disclosure to friends and family. Consequently, the authors created a measure based on findings from a qualitative study of disclosure conducted the same year with a sample of young adults with five different chronic conditions – congenital heart disease, kidney transplant, various rheumatologic conditions, cystic fibrosis, and spina bifida (Kaushansky et al., 2017). The measure was developed following review and feedback from the MyVOICE team and pediatric subspecialty providers. By creating a disclosure questionnaire, the study was able to quantitatively compare disclosure responses to validated and reliable measures commonly used with patients with chronic illness. It allowed for a measurable way to explore if disclosure practices were related to quality of life, psychiatric symptoms, coping, and responses to stress. The study examined decision-making considerations when disclosing to friends and family, such as characteristics of people to whom they disclose and the levels of depth of disclosure, ranging from transactional to sharing emotional or psychological impact of living with a chronic illness. Based on the thematic analysis of the data, a measure was created for the survey comprised of three sections of questions: (1) enumeration of friends and family members who know about their condition (e.g., How many people in your immediate family know about your condition (Mom, Dad, brother, sister, etc.?); (2) identification of friends and family with whom they feel most comfortable discussing their condition (e.g., Of all your friends, who do you feel most comfortable talking with about your condition? Why?); (3) depth of information they choose to disclose to this person (i.e., simple facts to disclosures of increasing specificity and/or intimacy). Levels of depth and specificity included diagnosis only, treatment and management of condition, condition-related limitations, information about condition, concerns/fears, and emotional/psychological issues related to condition. The measure was designed to further understand participants' social network's knowledge of their illness, reasons for disclosing, and the depth of information they disclosed, dimensions of disclosure that may help us understand the extent to which participants tended to connect disclosure to a sense of belonging and overall well-being. Therefore, data collected from this measure were analyzed with validated psychosocial assessments to explore the relationship between disclosure practices and mental health symptoms, coping strategies, quality of life, and responses to stress. The current analysis focused on disclosure to participants' friends. See Fig. 1 for survey items.

Mental health symptoms

A shortened version of the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), the Brief Symptom Inventory 18 (BSI 18), was used to assess mental health symptoms (Derogatis, 2001). The BSI was selected as it is widely used to assess psychiatric symptoms with youth and young adults with health conditions (Bryden et al., 2001; Kwak et al., 2013). This measure consists of 18 items reflecting three dimensions of psychological distress: anxiety (α = 0.84; M = 48.54, SD = 9.94), depression (α = 0.87; M = 51.46, SD = 10.24), and somatization (α = 0.81; M = 53.03, SD = 10.25). A summary scale score, the Global Severity Index (GSI), was used to assess overall distress (α = 0.93; M = 51.14, SD = 10.98). Participants were asked to indicate their level of distress over the past 30 days using a Likert scale ranging from 1 (not at all) to 5 (extremely). T-scores were calculated for all indices. T-scores greater than 63 indicated significant clinical symptoms.

Coping

The Brief COPE Inventory is an abbreviated version of the COPE Inventory designed to assess the frequency and use of different coping strategies (Carver, 1997). The Brief COPE captures individual differences in coping strategies and has been used in numerous studies examining coping with chronic illness (Lode et al., 2007; Tuncay, Musabak, Gok, & Kutlu, 2008). This 28-item measure includes 14 subscales with 2-items per subscale (Self-Distraction (α = 0.44), Active Coping (α = 0.73), Denial (α = 0.65), Substance Use (α = 0.90), Use of Emotional Support (α = 0.70), Use of Instrumental Support (α = 0.78), Behavioral Disengagement (α = 0.68), Venting (α = 0.48), Positive Reframing (α = 0.81), Planning (α = 0.52), Humor (α = 0.90), Acceptance (α = 0.72), Religion (α = 0.89), and Self-Blame (α = 0.70)). A 4-point Likert scale is used that ranges from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Following reverse scoring of some items, higher scores indicated greater use of the coping strategies. A factor analysis using principal components analysis with a direct oblimin (oblique) rotation was conducted. An Eigenvalue of 1 was utilized to determine the cutoff for extracting factors. As seen in Fig. 2, the analysis yielded two factors explaining a total of 38.2% of the variance. Factor 1 was identified as reflecting positive/adaptive coping (α = 0.80; M = 58.37, SD = 12.86) and Factor 2 reflected negative/maladaptive coping strategies (α = 0.69; M = 16.95, SD = 6.31).

Health-related quality of life

To assess the impact of one's health condition on physical, social, and emotional functioning, the Health-Related Quality of Life (HRQOL) questionnaire was administered (Andrinopoulos et al., 2011). The HRQOL was adapted from the Diabetes Quality of Life scale for youth to be used in research on HIV-infected adolescents and adults. The measure consists of three subscales based on the factor

Why do you feel most comfortable talking with this family member/friend about your condition?	They make you feel comfortable
	They are supportive of your condition
	They won't judge you
	They do not make you feel embarrassed
	They ask you questions
	They are a good listener
	They have a similar condition
	They understand you
	They understand your condition
	Other (specify)
What kind of things do you share with this family member/friend?	Your diagnosis
	Your treatment and management of your condition
	Limitations
	Information about your condition
	Concerns/ Fears
	Emotional/ Psychological issues related to your condition
	Other (specify)
(Regarding concerns in disclosure with friends) What kind of concerns do you have?	Fear of rejection
	They would be uncomfortable
	They would think less of you
	Embarrassment
	Ask questions you didn't want to answer
	They would think differently of you
	Other (specify)

Fig. 1 Disclosure questionnaire items (participants checked all that applied)

Brief COPE Factor Analysis					
Positive/Adaptive Coping (Factor 1)				Negative/Maladaptive Coping (Factor 2)	
Self-distract	.448, 409	Instrumental support	.699, .632	Denial	.522, .669
Emotional support	.638, .722	Positive reframing	.760, .735	Substance use	.604, .639
Humor	.438, .330	Planning	.681, .579	Venting	.591, .331
Religion	.448, .379	Acceptance	.586, .583	Self-blame	.730, .716
Active coping	.640, .612,			Behavioral disengagement	.754, .702

Fig. 2 Two-factor model of Brief COPE measure
Note: Pattern matrix factor loadings are provided for each of the two items within each subscale based on Principal Components Analysis using Oblimin Rotation Method with Kaiser normalization.

analysis by Andrinopoulos and colleagues: life satisfaction, illness-related anxiety, and illness burden (Andrinopoulos et al., 2011). A 5-point Likert scale was used for each subscale. In the life satisfaction subscale (9 items), Likert scale options ranged from 1 ("least satisfied") to 5 ("very satisfied") and items addressed current life satisfaction in regards to work or school, sex life, amount of time taken to manage their condition, knowledge of condition, appearance of their body, etc. (N = 132, α = 0.846; M = 35.4, SD = 8.06). For questions related to illness-related anxiety (8 items) and illness burden (13 items), Likert scale options ranged from 1 ("never") to 5 ("all the time"). The subscale of illness burden asked participants to rate how often their illness impairs or limits various domains of their lives including education, current/future jobs, and family life (N = 139, α = 0.836; M = 29.93, SD = 8.28). Illness-related anxiety subscale items examined worries about achieving future goals and adulthood milestones (N = 140, α = 0.856; M = 18.86, SD = 5.70). Higher scores on the HRQOL items and subscales indicate problematic concerns or dissatisfaction related to impact of health on one's life. Cronbach's alpha coefficients ranged from 0.836 to 0.856 indicating a high level of internal consistency.

Response to stress

The original Response to Stress Questionnaire (RSQ) is a 57-item multidimensional self-report assessment of responses to stress and coping (Connor-Smith et al., 2000). For this study, the first 11 items of the RSQ were included to explore the degree to which illness-specific events have been stressful over the past six months. Likert-scale items ranging from 1 ("Not at all") to 4 ("a lot") were modified to address a range of chronic health conditions (e.g., "Missing days at school/work", "Worrying that my condition will get worse", "Not understanding what doctors tell me about my condition"). The RSQ demonstrates adequate to excellent internal consistency and retest reliability when used with adolescents (Connor-Smith et al., 2000). Higher scores indicated greater experienced stress related to their chronic health condition (Range = 11–41; M = 23.24, SD = 7.62, α = 0.89).

Table 2 *Percent of responses to "Information Disclosed to Friends" item*

Information Disclosed	Percent
Diagnosis	59.3%
Treatment and Management	52.9%
Limitations	41.4%
Information about Condition	54.3%
Concerns and Fears	40.0%
Emotional and Psychological Issues	36.4%
No Information Disclosed	14.29%

Data analysis plan

The data were analyzed using SPSS Statistics Software 17.0. The entered data set was reviewed for missing data prior to the analysis. There was complete data for sufficient power for proposed analyses. If participants had missing data in a subscale or measures, they were included in analyses in which they had complete data. Distributional data for outcomes was reviewed. The following variables were identified with significant skew: HRQOL – illness burden subscale; Brief COPE – negative coping index; and, Brief COPE subscales for Denial, Substance Use, Behavioral Disengagement, Acceptance, and Religion. These variables were transformed using a log function to normalize the data and analyses utilized these transformed outcome variables. Chi-square analyses were used to examine demographic differences (i.e., gender, age) across the three disclosure groups. To analyze differences in coping strategies, responses to stress, and health-related quality of life across the three disclosure groups, multiple one-way analysis of variance (ANOVA) and one-way multivariate analysis of variance (MANOVA) were performed.

Results

Descriptive data for the sample, including demographic information and covariates, is presented in Table 1. Most participants indicated that they shared their diagnosis to at least one person in their friend network and over a third shared more personal information related to their emotional and psychological concerns related to their medical condition. Twenty participants reported disclosing to no one (See Table 2).

To understand the depth of information participants disclosed to friends, participants checked all the levels of disclosure that applied to them -- diagnosis only, treatment and management of condition, condition-related limitations, information about condition, concerns/fears, and emotional/psychological issues related to condition. Responses were collapsed into three categories that were conceptually coherent. Participants were categorized into these three groups based on the item they selected indicating the most intimate information they were comfortable disclosing. The first 'No Disclosure' group (n = 20) included participants indicating that they do not disclose any information about their chronic medical condition to friends. The 'Facts' group (n = 55) included participants who reported sharing only objective information about their condition (diagnosis only, treatment, limitations, and information about condition) to friends. Lastly, the 'Concerns/Emotion group' (n = 65) was comprised of participants who disclosed concerns, fears, and emotions related to their chronic illness.

The initial analysis explored demographic differences in depth of disclosed information to friends. Gender differences across disclosure groups were examined using a chi-square test of independence. Gender differences were significant, c^2 (2, $N=140$) $=8.30$, $p=.02$, indicating that male participants tended to disclose ‘Facts’ to friends while female participants tended to disclose ‘Concerns/Emotions.’ In addition, participants in a romantic relationship were compared to those reporting they were single. A chi-square test of independence indicated a trend towards significance between groups (c^2 (2, $N=137$) $=5.69$, $p=.06$), suggesting that those in a relationship tended to share ‘Concerns/Emotions’ while single participants tended to disclose only ‘Facts’ related to their medical conditions. Age differences were explored across the three disclosure groups using a one-way ANOVA. There was a statistically significant difference in age between groups ($F(2, 137)=4.68$, $p=.01$). A Bonferroni post hoc test revealed that the ‘No Disclosure’ ($M=17.65$) group was significantly younger than the ‘Facts’ ($M=18.73$) and ‘Concern/Emotions’ ($M=18.57$) groups. Due to the small sample sizes across subspecialty services, a chi-square test of independence was conducted using the two most represented subspecialty services, nephrology and rheumatology, as participants from these two services made up approximately 70% of the sample. No significant differences were found between the disclosure groups across these two subspecialty services. Participants were asked to share the total number of friends that know that they have a chronic medical condition, which was categorized into four ranges: 0, 1–3, 4–8, and over eight friends. Participants reporting they disclosed to nine or more friends were significantly more likely to share ‘Concerns/Emotions’ to their friends compared to those who indicated that fewer friends know of their condition (c^2 (6, $N=140$) $=29.02$, $p<.01$).

Table 3 displays the results of three one-way ANOVAs examining the differences between disclosure group memberships and self-reported health-related quality of life subdomains. Post hoc analysis revealed that the ‘Concerns/Emotions’ group had significantly higher Illness-Related Anxiety than the ‘Facts’ group. ($F(2, 137)=2.99$, $p=.05$). We found no significant differences between disclosure groups and Life Satisfaction and Illness Burden subscales.

The relationship between disclosure groups and response to illness-related stress as measured by the RSQ reveal a statistically significant group difference in responding to illness-specific stress ($F(2, 137)=2.99$, $p=.05$). Tukey’s HSD post hoc test indicated that the ‘Concerns/Emotions’ group reported greater stress in response to illness-related events than the ‘Facts’ group ($p=.05$), with a 95% confidence interval of the difference between the means (2.4) between -0.04 and 4.84.

Mean scores for each of the mental health domains of the Brief Symptoms Inventory were not clinically significant (i.e., mean T-scores less than 63). Additionally, there were no significant group differences in mental health symptoms on symptoms of depression, anxiety, or somatization or on the BSI Global Severity Index.

Using one-way MANOVA, we found differences in coping strategies across disclosure groups, applying the two-factor structure – positive and negative coping -- determined by the factor analysis of the Brief Cope measure (Fig. 2). Results indicate significant differences across disclosure groups in using positive coping strategies ($F(2, 137)=4.131$, $p=.02$), with significance found between the ‘No Disclosure’ and ‘Concerns/Emotions’ groups such that the ‘Concerns/Emotions’ group reported significantly greater positive coping ($p=0.04$), with a 95% confidence interval of the difference between the means (8.04) between 0.45 and 15.70.

To further explore between-group differences on the types of positive strategies being utilized, individual subscales of the Brief Cope were compared across each disclosure group. One-way ANOVAs demonstrated statistically significant group differences in utilizing Positive Reframing ($F(2, 137)=3.41$, $p=.04$) and Emotional Support ($F(2, 137)=3.58$, $p=.03$) coping strategies. Tukey’s HSD post hoc tests revealed that the ‘Concerns/Emotions’ disclosure group engaged in higher levels of positive reframing as a coping strategy compared to the ‘Facts’ group ($p=.04$), with a 95% confidence interval of the difference between the means (0.96) between 0.02 and 1.89, and utilized more emotional support than the ‘No Disclosure’ group ($p=.04$), with a 95% confidence interval of the difference between the means (1.29) between 0.03 and 2.54.

Table 3 *Mean Comparison of Subdomain Scores of the HRQOL Between Groups*

	No Disclosure Mean (SD)	Facts Mean (SD)	Concerns/Emotions Mean (SD)	*F*	*df*	*p*
Life satisfaction	30.90 (7.97)	34.06 (7.31)	32.55 (6.51)	1.58	129	0.21
Illness Burden	28.90 (10.10)	29.46 (8.46)	30.63 (7.57)	0.47	136	0.63
Illness-Related Anxiety	18.00 (6.84)	17.71 (5.81)	20.11 (5.02)	2.99	137	0.05*

Discussion

The present study sought to deepen our understanding of how disclosure practices among adolescents and young adults with a variety of chronic illnesses are related to mental health and health-related quality of life. To our knowledge, developmentally appropriate measures designed to quantitatively capture disclosure strategies for this population do not exist. We created a tool based on past qualitative research and solicited input from pediatric providers that explores the number and characteristics of people with whom they disclose information about their conditions and the range and depth of content adolescents and young adults are comfortable disclosing to their friends (Kaushansky et al., 2017).

Three different disclosure profiles emerged from the data reflecting a spectrum of depth of information AYA were disclosing to friends. Participants in the 'No Disclosure' group (n = 20) denied sharing any illness-related information to their friends. This group was younger with the mean age under 18 while the mean ages of the other groups were over 18 years old. This may suggest a shift in openness to disclosing information about their condition as youth age out of high school and, developmentally, may be less concerned about peer rejection which can be amplified in secondary school settings (Furman & Buhrmester, 1992; Newman & Newman, 2001). The 'No Disclosure" group also reported lowest use of positive coping strategies.

Two larger groups emerged – the 'Facts" group (n = 55), participants who reported a more transactional information exchange, disclosing diagnosis, treatment, limitations, and information about the condition, and the 'Concerns/Emotion' group (n = 65), reporting that they disclosed more personal information related to their illness including concerns, fears, and emotional/psychological issues. We found female participants were more likely to disclose concerns and fears while males disclosed more factual information. This finding aligns with existing research on gender differences suggesting that young adult females are found to be more likely to seek out social support using emotion-focused coping than males in response to stress (Brougham et al., 2009).

An area worthy of further examination is exploring how disclosure practices and decision-making play out in the context of romantic relationships and dating. Although not reaching significance, there was a trend observed of participants who identified as being in a romantic relationship sharing greater depth of information about their condition compared to those who were single. Qualitative inquiry could shed light on decision-making related to disclosure among youth forming or engaging in relationships. Further, it would be worth exploring how and if anxiety about intimacy and worries about the future relates to perspectives on maintaining relationships, marriage, fertility, the ability to raise children, and life expectancy.

Participants who reported disclosing to nine or more friends were more likely to share 'Concerns/Emotions' to friends than those who indicated that fewer friends knew of their condition. These participants, who also exhibited positive coping profiles, may experience greater comfort in disclosing in general as more friends not only know of their condition but were told more personal information related to their illness.

The significant relationship we found between participants in the 'Concerns/Emotions' group and illness-related anxiety and stress supports our hypothesis that those with higher degrees of health-related anxiety and stress would be more inclined to seek out friends with whom they can share their concerns related to their illness. While this appears to be a positive finding, reinforced by the evidence that this group is more inclined to employ positive coping strategies, we cannot know the extent to which disclosing these concerns had on psychological well-being. It is promising that it appears that that instead of isolating from friends, perhaps due to fear of rejection or not feeling understood by peers, this group is actively seeking out and sharing their emotional experiences with friends. Participants in the 'Concerns/Emotions' group engaged in significantly greater positive coping strategies, specifically positive reframing and emotional support, than those who chose not to disclose their condition to friends providing further evidence of the relationship between the utilization of social support and positive coping strategies (Edgar & Skinner, 2003). Given that this is a cross-sectional study, we are unable to determine the processes by which more intimate disclosure and emotional support-seeking are developed. Longitudinal research on the development and evolution of disclosure patterns and support-seeking as youth with chronic illness move through adolescence into young adulthood would contribute to our understanding of the development of positive coping strategies in response to illness-related stress.

Interestingly, BSI scores of psychological symptoms were not clinically elevated across the three groups and no group differences emerged. Yet, analyses examining the HRQOL and RSQ measures that specifically connect worries and anxiety to experiences of having a chronic condition, revealed a greater amount of psychological distress among participants. Mental health assessment of AYA with chronic illness is an increasingly common practice in pediatric subspecialty care. These findings suggest that broader measures of psychological symptoms, like the BSI, may be eliciting very different responses from patients than measures that explicitly link the experience of living with and managing a medical condition with psychological symptoms. The field may be inadvertently missing an important opportunity to accurately assess mental health status and connect these young people to mental health services to target distress related to living with their condition. Understanding that many mental health screening measures are designed to be brief and broad due to time constraints on physicians and the need to screen a broad range of individuals (Weitzman et al., 2015), incorporating questions about illness-related anxieties may provide a more accurate assessment of psychological well-being.

This study contributes to the expanding literature on disclosure strategies among young people living with chronic illness who are simultaneously navigating the social and psychological vicissitudes and challenges typical of adolescent development (Barker et al., 2012; Benson et al., 2015; Kaushansky et al., 2017; Woodgate et al., 2020). Considering the lack of quantitative studies exploring disclosure strategies in adolescents, we cannot at this time make assumptions about how varying disclosure strategies impact psychological well-being, but we can demonstrate different profiles of disclosure across different age groups and a variety of chronic conditions. It is critical to examine issues related to disclosure among younger versus older adolescents and young adults given the developmental importance of social support and the role of social networks on psychological and physical health (La Greca et al., 2002). AYA with chronic health conditions interact frequently with medical professionals, which presents multiple opportunities to assess disclosure practices, the nature of their support networks and the kinds of issues young people are sharing with friends. We can benefit from further qualitative and quantitative research with this population to establish a deeper understanding of the perceived and experienced benefits of disclosure and the impact of disclosure on feared stigma in adolescents with chronic illnesses. A follow-up survey of these participants as they move into young adulthood will provide insight into how disclosure patterns and information shared might change as their health and social identities, environment, and experiences evolve.

There are several limitations of this study to note. While a priori power analyses were conducted to determine the study's overall sample size, an a priori power analysis was not conducted for this specific analysis, such that limited power may have impacted our ability to detect significant relationships between variables that may exist. Moreover, though we obtained a moderate sample size overall, we were limited in our ability to make comparisons across diagnoses or medical sub-specialty. Further exploration of the impact of disease visibility, recency of diagnosis, and acuity of the illness or recent experiences of a health-related event on disclosure decision-making will enhance our understanding of the disclosure process. Additionally, there are caveats regarding the factor analysis conducted, given small sample size and limited power, though the results still indicated acceptable reliability and significant associations with other variables. Moreover, while a strength of our sample is the diversity of conditions and inclusion of participants from adolescence through young adulthood, there are likewise limitations associated with the generalizability of data given the range of diversity of their lived experiences. Longitudinal studies designed to explore disclosure strategies and outcomes over time will help to better identify factors associated with changes made in disclosure practices related to key developmental changes that occur entering adulthood. The study involved primarily participants who identified as Latinx/Hispanic (81.4%) with significantly smaller representation from other ethnicities; therefore, group differences were not examined. Racial/ethnic and cultural differences in disclosure practices should be a focus for future studies. Finally, while an increasing number of youth living with chronic illness have engage with social media as a platform for emotional and instrumental support (De Nardi et al., 2020), this was not an area of focus for the present study. Future studies should further examine the ways in which AYA with chronic health conditions utilize social media and the ways in which these interactions might support their mental health and well-being (Kelleher et al., 2020).

Future studies could benefit from a rigorous process to develop and test the validity of nuanced measures designed to capture disclosure experiences and practices, such the measure described in this study. Appropriate clinical interventions can then be designed to target disclosure strategies based on the results of these measures. For instance, Interpersonal Psychotherapy (IPT), a structured, time-limited, evidence-based practice developed to address depression with specific foci on grief/loss, interpersonal disputes, role transition, and interpersonal sensitivity (Lipsitz & Markowitz, 2013), has been adapted to address the unique experiences of adolescents and adults with chronic health conditions (Chan, 2005). Such an intervention may provide therapeutic support in individual and group settings to assist with healthy, adaptive disclosure and promote positive coping with illness-related stress.

Conclusion

This study contributes to a limited literature examining the relationship between health-related disclosures and mental health outcomes for adolescents and young adults living with chronic illness. Our findings highlight that youth with greater emotional and psychological impact from their condition may use disclosure in order to gain further support, particularly using such disclosure as a positive coping strategy. Further, it may be beneficial for clinicians working with youth living with chronic illness to assess the impact of their condition on their mental health earlier on in their diagnosis and consider strategies for augmenting their access to social support. In addition, this study offers insight into ethnically and socio-economically underserved populations seldom represented in the current literature on disclosure, highlighting the need for greater exploration into the interaction between socio-cultural factors and disclosure practices. Adolescence is a developmentally primed time for making disclosure decisions to friends or family across a variety of identities, including sexual and gender identities, mental health diagnoses, and relationship status. In continued efforts to decrease the sense of stigma for many with concealable and visible identities, the impact of disclosure on psychological health, resilience, and coping is of clinical importance and merits additional research.

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Data Availability All data and materials as well as software application or custom code support our findings and comply with field standards. The data generated and/or analyzed for the current study are available from the corresponding author upon reasonable request.

Declarations

Conflict of Interest On behalf of all authors, the corresponding author states there is no conflict of interest.

Ethics approval This study was reviewed and approved by the Institutional Review Board of Children's Hospital Los Angles and certify that the study was conducted in accordance the ethical standards articulated in the 1964 Declaration of Helsinki and its later amendments.

Consent to participate/Consent for publication Written informed consent was obtained from all study participants which included consent for publishing their data. Parents or legally authorized representatives of participants 15–17 years of age provided written consent for their children.

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